Sexual orientation disclosure in healthcare: systematic review

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ABSTRACT

Background

Significant health disparities between sexual minority individuals (i.e. lesbian, gay, bisexual or transgender (LGBT)) and heterosexual individuals have been demonstrated.

Aim

To understand the barriers and facilitators to sexual orientation (SO) disclosure experienced by lesbian, gay, bisexual and transgender (LGBT) adults in healthcare settings.

Design and setting

Mixed methods systematic review, including qualitative, quantitative and mixed methods papers following PRISMA guidelines.

Method

Study quality was assessed using the Mixed Methods Appraisal Tool (MMAT) and then underwent a qualitative synthesis. Studies were included if their participants were ≥18 years who either identified as LGBT, had a same-sex sexual relationship or were attracted to a member of the same-sex.

Results

The review included 31 studies representing 2442 participants. Four overarching themes were identified as barriers or facilitators to SO disclosure, the moment of disclosure, the expected outcome of disclosure, the HCP, and the environment or setting of disclosure. The most prominent themes were the perceived relevance of SO to care, the communication skills and language used by HCPs and the fear of poor treatment or reaction to disclosure.

Conclusion

The facilitators and barriers to SO disclosure by LGBT individuals are widespread but most were modifiable and could therefore be targeted to improve HCP awareness of their patient's SO. HCPs should be aware of the broad range of factors that influence SO disclosure and the potential disadvantageous effects of non-disclosure on care. The environment in which patients are seen should be welcoming of different SOs as well as ensuring HCP communication skills, both verbal and non-verbal, are accepting and inclusive.

Keywords: General practice; sexual orientation (SO); disclosure; LGBT; review

How this fits in

Significant health disparities exist between sexual minority (i.e. lesbian, gay, bisexual or transgender (LGBT)) and heterosexual individuals. Disclosure of SO in healthcare links to both the minority stress and fundamental cause theories in the context of accessing appropriate services, and is therefore likely to be a contributing factor in these health differences. Incorporating more LGBT-specific knowledge and communication skills into undergraduate medical education is essential in aiding SO disclosure. Altering the healthcare environment such as displaying signs or symbols that convey an accepting atmosphere, such as a rainbow symbol or the Human Rights Campaign logo may also help.

INTRODUCTION

Significant health disparities between individuals identifying as part of a sexual minority (i.e. lesbian, gay, bisexual or transgender (LGBT)) and heterosexual individuals have been demonstrated internationally. [1 2] In the UK, sexual orientation (SO) is a protected characteristic under the Equality Act (2010) [3] which requires public services to promote and demonstrate the equality for LGBT people. A large component of proving compliance with this mandate is monitoring SO, which is currently poorly done in the UK. National estimates of the adult LGBT population range from 1.7%[4] to 9.9%,[5] though the validity has been questioned. [6] This has been recognised as a significant issue and NHS England has worked with the LGBT Foundation and National LGB&T Partnership to implement a SO monitoring information standard from April 2017. [7]

Health disparities between heterosexual and LGBT people are still seen in mental health, with higher rates of anxiety and depression, self-harm, and suicide[1 8-12] among the LGBT community, as well in physical health. A recent UK-based review reported increased rates of some malignancies in the LGBT community, mixed diabetes rates and higher rates of substance abuse, including binge drinking and smoking. [1] Differences between sexual minority groups has also been reported, showing poorer mental and physical health in bisexual people of both sexes[9 10 12] as well as higher rates of high risk health behaviours such as smoking and excess alcohol intake. [1 8 9 11] It has been noted that robust evidence comparing the different groups that make up the LGBT community is lacking, [1] particularly in reference to transgender, queer and intersex persons.

The most prominent theory for differences in health by SO is minority stress. [13 14] This hypothesises that a combination and accumulation of internal and external stressors (such as stigma and victimisation and the distress felt in response to stigma and concealment of one's SO) interact to overcome an individual's ability to cope, resulting in psychological and physical disease.[14] A further theory is fundamental causes, which posits that advantaged groups in society have the skills and resources necessary to minimise risk of disease as well as to harness the appropriate health resources to lessen the consequences of disease should it occur. [15] A Swedish study has presented support for the fundamental cause theory applicable to the LGBT community, describing increased rates of high-preventable diseases such as ischaemic heart disease, chronic obstructive pulmonary disease (COPD) and lung cancer in LGBT people compared to heterosexual people. [16]

Disclosure of SO in healthcare links to both *the minority stress and fundamental cause theories* (detailed above) in the context of accessing appropriate services, and is therefore likely to be a contributing factor in the health differences. In line with this, a recent British review found that many LGBT people are reluctant to disclose their SO, and will sometimes delay care due to fear of disclosure, even in the face of inappropriate or less appropriate care. [17] The purpose of our review was to investigate the barriers and facilitators to SO disclosure in healthcare by LGBT adults, with the aim of identifying factors that can be easily modified in healthcare education and practice to improve disclosure and therefore ensure provision of appropriate care.

METHODS

This review has been registered on the PROSPERO international prospective register of systematic reviews, number CRD42017056079.

Search strategy

A search of eight databases (AMED, CINAHL, EMBASE, MEDLINE, PsycINFO, RCNi, ScienceDirect, and Web of Science) was conducted in March 2017. Terms were chosen to include all standard genders and minority SOs, focusing on SO disclosure in healthcare settings or to a healthcare professional. The final search conducted was: ((disclos* OR reveal* OR openness) AND (lgb* OR gay OR bisexual OR lesbian OR msm OR wsw OR homosex*) AND (health* OR care OR consult*)). We excluded all editorials, commentaries, reviews and conference abstracts. Only articles published after 2000 were considered to ensure recent barriers and facilitators were captured and only those in English were included.

Inclusion and exclusion criteria

Participants were aged 18 years or above and samples contained at least some self-identified as LGBT. Further, only studies that displayed data provided by the participants on the barriers and/or facilitators to disclosure (or nondisclosure) of SO to a healthcare professional were included. Studies that did not specify disclosure to a healthcare professional or those outside a healthcare setting were excluded. Whilst we recognise that transgender is a gender identity rather than a SO, we have included transgender as we were unable to disaggregate transgender from LGB data.

Study selection and data extraction

The process of systematic review is summarised using the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) [18] (Figure 1). Data were extracted using a proforma followed by qualitative analysis.

Assessment of study quality

The Mixed Methods Appraisal Tool (MMAT) [19] was used to assess methodological quality. Two screening questions and four criteria for assessment were applied to each study, scoring sampling, measurement, analysis and limitation consideration. This gave a score ranging from 0% (no criteria met) to 100% (all four criteria met) for each paper, allowing one robust score to be used for multiple study types. Quality assessment was carried out by three assessors. Kappa scores were calculated to assess inter-rater variability.[20]

RESULTS

Studies identified

From 2603 records, a total of 31 studies met the inclusion criteria (Figure 1). Six studies presented data relevant to disclosure solely in a primary care setting, three in oncology, three in military medical settings, and one each in mental health and a home care settings. Eleven studies did not state or did not specify a precise healthcare setting but instead presented data from generic health settings and six presented data from a variety of settings. In total, 2442 participants were included across the 31 studies identified for review.

Data synthesis

The barriers and facilitators identified are presented in four overarching themes (Table 2).

The moment of disclosure

Twenty studies commented on patient's beliefs of the relevance of SO to healthcare as both a barrier and facilitator to disclosure – people who thought it was relevant were more likely to disclose[21-31] whilst those who thought it was irrelevant were less likely reveal their identity. [22 24-26 28-30 32-40] One participant felt the need to disclose to enable their HCP to provide "more focused advice" [25] and another thought their "gayness to be highly relevant to [their] health needs". [22] Other's asked "what's [my SO] got to do with, you know, my toe hurting?" [29] and felt "[SO] would only be important if a problem was discovered." [37]

Communication factors such as using inclusive language[31 35 37 41 42] and open, welcoming body language[24 35 37 42-44] were seen as facilitators to disclosure whilst the opposites; closed-off or unfriendly body language[42] and heteronormative language[27 35] such as using a male pronoun to identify a female patient's partner, and vice versa, were viewed as barriers. There were mixed opinions on the merits of using direct questions to explore a patient's SO. The majority of participants appreciated being asked and felt this was a good way to facilitate open communication between patient and provider[22 24 27-29 32 34 35 37 38 40 42 45 46] but a small number did not agree. [26 28 31 42] There were similarly mixed views of the benefits of patient registration forms to document SO. Some described their delight at finding a registration form that included their SO as an option[36] whilst many felt their SO was not accommodated by the options presented. [27 37] Most described these types of written disclosure as a facilitator to disclosure, [23 36 40 42 43 47] but only if they were adapted to be more inclusive and depict a broad spectrum of SOs. [23]

The final barrier at the moment of disclosure was the patient's response to heteronormative assumptions. This was most commonly identified in the context of contraception and sexual health, with the giving of only heterosexually-appropriate advice. [28 31 32 46]

Perceived outcome of disclosure

Fear of discrimination, including receiving poor or unequal care, [24 27-30 33 41 44 46 48 49] having a negative impact on their career[26 44] or benefits[26 29] as well as criminalisation[44 50] were all cited as reasons not to disclose. Further, many participants were hesitant to disclose for fear of a negative personal reaction from their HCP. [24 25 30 31 38-42 44 47 49 50] or feeling embarrassment or humiliation after disclosure. [32 34 38 40 47] Many participants cited concerns of breaches in patient-provider confidentiality[21 25 30 35 38 40 44 47 48 50] that would lead to non-clinical staff, [48] their family and friends, [35] or the wider community[44 50] discovering their SO as reasons not to disclose. Similarly, documentation of SO in medical records was seen as a barrier to disclosure.[25 26 29 30 47]

Healthcare professional factors

The majority of patients were more likely to disclose to a HCP with whom they had a long relationship.[24 40 48] Seven studies reported an increased likelihood of disclosure if the HCP was themselves a member of the LGBT community. [21 26 33 39 42 47 49] While having a heterosexual HCP was not seen as a particular barrier to disclosure, a HCP being perceived as accepting of the LGBT community, or of their patient being LGBT, was a significant facilitator. [33 35 40 41 44 47]

Environmental factors

Some participants preferred to disclose their SO in sexual health clinics rather than to their primary care provider. [34] On the other hand, military[45] and religious-affiliated[33] settings were seen as impeding disclosure, as was care conducted in a group treatment setting. [40] Most notably, seven studies commented on visual clues in the healthcare setting that facilitated disclosure. [24 27 40 42 43 49 51] These

included seeing leaflets, stickers and posters that were deemed LGBT friendly, like the Human Rights Campaign logo or a rainbow sign. [42 43 49] Religious symbols or icons displayed in the HCP setting were barriers. [24]

DISCUSSION

Summary

In the UK, it is estimated that only half of lesbian and gay people are out to their general practitioner (GP), with disclosure rates lower in bisexual people. [17] We have found that the factors promoting or discouraging patient SO disclosure in healthcare are widespread and varied. The most commonly cited factors were associated with the patient-provider interaction, which may provide useful targets to improve disclosure rates.

Factors which were deemed to either enhance or reduce SO disclosure amongst females were having SO documented in their medical record and using written forms as a means of disclosing SO as well as the type of language used during a consultation . Perhaps the use of prompts to aid disclosure, such as having a partner, a written form or picking up on clues from the HCPs speech, are more important to LGBT women than men as they may be more commonly assumed heterosexual, particularly in discussing their reproductive health, [31 52] and are less frequently asked directly about their SO. [29]

Whilst almost all were conducted in countries where homosexuality is legal, two were not. In both these studies, barriers to disclosure were almost exclusively explored; commonly the effect of an unsupportive community, fears of discrimination, and breaches in confidentiality were described by participants. They were, unsurprisingly, the only two studies to mention criminalisation as a barrier. Although the factors explored were often extreme, ranging from not being treated by their HCP at all, to the police being informed of participant's SO and fears of being ostracised from their community, they were echoed to a lesser extent in studies based in other countries.

Strengths and limitations

While this is the first review to include participants that are both men and women as well as participants from any sexual LGBT subgroup, there are some limitations. The MMAT has shortcomings. Although allowing us to assess different study types with one tool, we often found it difficult to assess the methodological qualities of each study without assessing the quality of reporting. Further, we found the MMAT criteria to be fairly crude measures of quality, particularly for qualitative studies. The quality assessment was not taken into account when extracting data from each study, with all the evidence being treated equally. Additionally, most of the mixed methods studies had particularly weak evidence from the quantitative branch of the study. The richest and most appropriate data was extracted from the qualitative arms.

The studies included for review also have limitations. Sampling the LGBT community is recognised as difficult due to the hidden nature of the population. We recognise participants need to have disclosed their SO before being recruited to studies, so may not have the same barriers and facilitators to disclosure as those that had not disclosed at all. Further, the participants from each study were largely homogenous, comprising of mostly well-educated, white, middle-aged people, which are the groups most likely to disclosure their SO. [53-56]

Comparison with existing literature

Studies with only correlates of SO disclosure were excluded as they were outside the remit of this review. They do include, however, important information on the effects of patient gender, age, ethnicity and SO on disclosure. For example, LGBT people who are from ethnic minorities, [53-56] or identify as bisexual, [53 54 56-58] or do not have a college education, [54 55 59] or have a low income[54 55] are less likely to disclose their SO to a HCP. There is mixed evidence for the effect of patient age[54 55 59] and gender[17 53 60] on disclosure. These are important factors to consider when implementing interventions in terms of targeting population groups.

Although useful to enhance our understanding of demographics and disclosure, the quantitative data also supports our, predominantly qualitative, findings. For example, a recent paper from Canada found that higher levels of self-esteem, having a partner and higher levels of social support from friends were significantly associated with HCPs knowing a patient's SO, while participants with previous experiences of discrimination and higher levels of internalised homonegativity were less likely to discuss LGBT-related health issues with their HCPs. [61]

Implications for research and/or practice

Whilst some of the factors identified in this study are fixed, some could be targeted to minimise the barriers to disclosure. Five of the studies in this review commented on HCP's lack of LGBT-specific knowledge as a barrier to disclosure. This problem stems from the beginning of medical education, with one study noting a median of five LGBT-dedicated curriculum hours in USA medical schools[62] and another study showing medical students in the UK lacking confidence in the use of LGBT-specific health terms and their ability to locate LGBT-specific health information. [63] Incorporating more LGBT-specific knowledge and communication skills into undergraduate medical education is essential to ensure our future HCPs are armed with the tools they need to help their future patient's disclose their SO and then provide them with appropriate care and advice. The responsibility for medical education does not just sit within the undergraduate realm; there should be increased presence of LGBT-specific issues and appropriate communication tools in postgraduate curricula also.

At an institutional level, the design of healthcare settings should take into account the needs of LGBT patients. There are some changes that are easily implemented and inexpensive, including displaying signs or symbols that convey an accepting atmosphere, such as a rainbow symbol or the Human Rights Campaign logo, whilst others may take more time. It is important to ensure, however, that any healthcare setting changes are congruent with the beliefs of the HCP working within them. A key intervention is the production of patient information leaflets that are accepting of the LGBT community and that consider the differing needs of LGBT individuals compared to heterosexual individuals, providing LGBT-specific information when necessary.

Individual HCPs should be aware of the differing physical and psychological needs of the LGBT community and remain open-minded regarding their patient's SO. We encourage all HCPs to reflect on their use of language, keeping an eye out for heteronormative phrases and assumptions, as well as those that may be inhibiting their patient's ability to disclose, and consider using alternative terms. The most common example of this is referring to a patient's partner as 'he' or 'she' rather than asking whether they are male or female or going further to ask whether the patient has, or ever has been, involved in a relationship with men, women or both. HCPs should also consider asking questions about each patient's SO in their daily practice, using open and accepting language. Further investigation into issues surrounding disclosure from a HCP perspective would also provide a fuller understanding of the complexities surrounding SO disclosure in healthcare.

Ideally, we need robust population-level studies that include an accurate portrayal of the breadth encompassed within LGBT. The current SO monitoring question in the UK has only 5 possible answers (heterosexual, gay/lesbian, bisexual, other, prefer not to say) which do not display the full spectrum of orientations and focus only on sexual identity rather than attraction or behaviours. For example, an alternative means of monitoring who describes themselves as ‘other’ would allow a much richer, and much needed, analysis of the population.

STATEMENTS/DECLARATIONS

Competing interests

"All authors have completed the ICMJE uniform disclosure form and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work."

Contributorship

CL, CJJ, AP, TN, FCP and FDSG devised the search terms and TN, FCP and FDSG performed the initial literature search. FCP, FDSG and HB performed the study selection process, with support from CL and CJJ. HB drafted the paper and performed the repeat literature search. All authors revised the draft paper. CL and HB acts as guarantors.

Ethics

Ethical approval was not required for this study.

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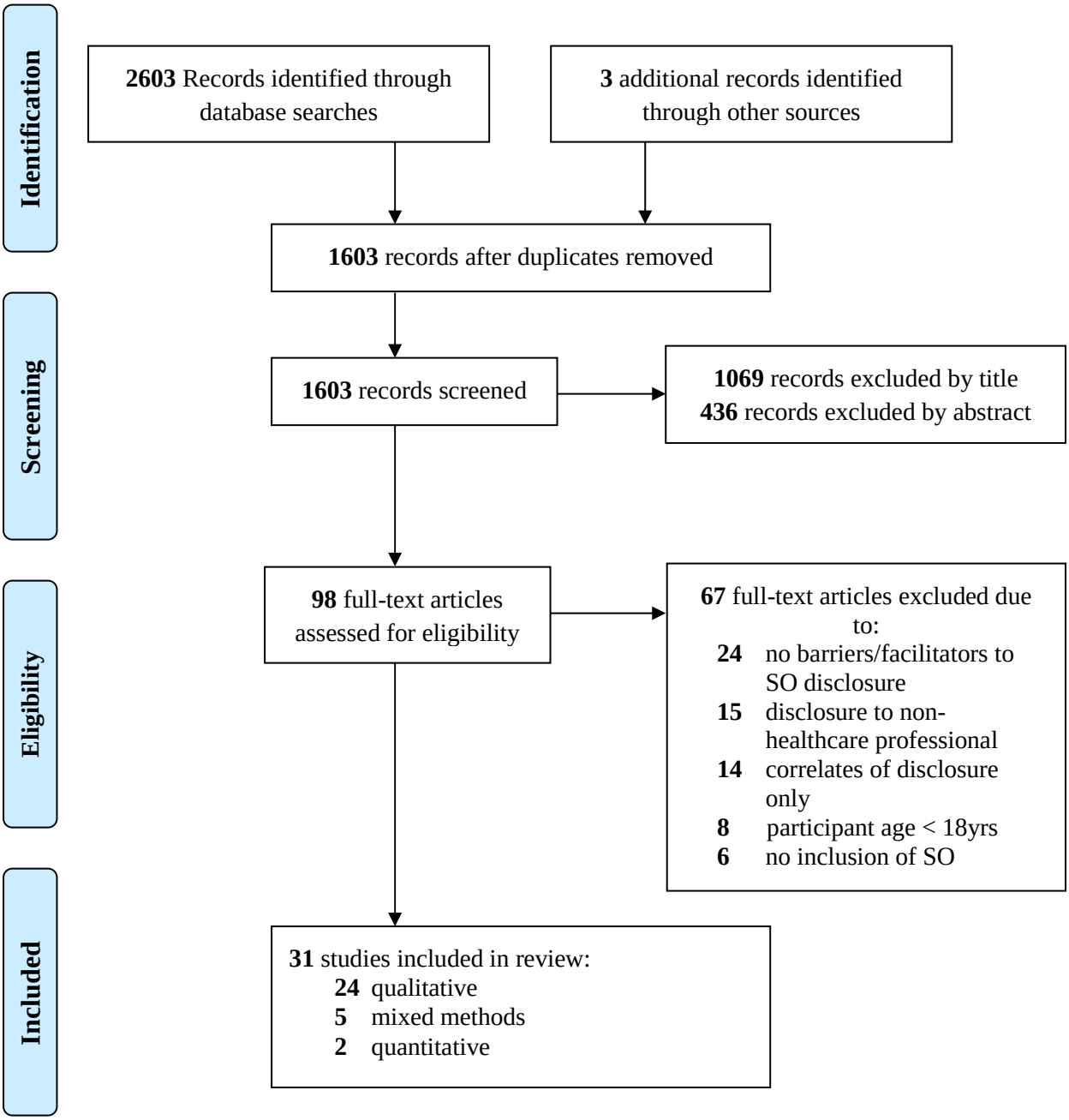

Figure 1 – Preferred Reporting Items for Systematic Review and Meta-Analysis flow diagram for the inclusion of studies reporting barriers and facilitators to sexual orientation disclosure in healthcare

Table 1 – Characteristics of studies included in the review (presented in chronological order)

Author (Publication Year) Country	Healthcare Speciality	Study population	Selected sample characteristics (Age, ethnicity, education level)	Sample size
Barbara[47] (2001) USA	Not stated	Lesbian women	Age range 24-65 69% white 90% some college education	32
Beehler[22] (2001) USA	Primary care	Gay men	Median age 38 (range 25-52) 82% white 91% some college education	11
Stein[30] (2001) USA	Range - 77% primary care	Men and women of any sexual orientation	Mean age 45 (range 19-83) 76% white 80% at least college education	575
Boehmer[33] (2004) USA	Oncology	Lesbian and bisexual women	Mean age 49 (range 26-67) 94% white 97% at least college	39
Clover[49] (2006) UK	Not specified	Gay men	Age range 60-75 100% white	10
McDonald[51] (2006) Canada	Not specified	Lesbian women	Age range 26-56 100% Caucasian 73% at least some college education	15
Bjorkman[41] (2007) Norway	Primary care	Lesbian women	Mean age 41 (range 28-59) all Caucasian all well educated	6
Mulligan[36] (2007) Australia	Not specified	Lesbian and bisexual women	Age range 20-71	47
Adams[21] (2008) New Zealand	Primary care	Gay men		50

Author (Publication Year) Country	Healthcare Speciality	Study population	Selected sample characteristics (Age, ethnicity, education level)	Sample size
Bjorkman[32] (2009) Norway	Any, majority primary care	Lesbian women	Age range 18-60+ (68% aged 20-39) 87% Norwegian native 67% some college education	121
Politi[37] (2009) USA	Not specified	Women of any sexual orientation	Mean age 55 98% white 73% at least college education	40
Daley[42] (2012) Canada	Mental health	Lesbian women	Age range 20-58 83% white	18
Biddix[45] (2013) USA	Military	Gay and bisexual men	Age range 18-47 (56% 18-27) 86% white 91% some college education	30
Johnson[23] (2014) USA	Not specified	Non-heterosexual women	Mean age 20 (range 18-23) 77% white all university students	9
Koh[24] (2014) Australia	Primary care	Lesbian, gay, bisexual or transgender men and women	Modal age 20-29 (range 18-60+)	99
Sharek[39] (2014) Ireland	Range	Lesbian, gay, bisexual or transgender men and women	59% aged 55-59 years	144 survey + 36 interview
Sherman[29] (2014) USA	Military	Lesbian, gay, bisexual or transgender men and women	>50% aged 40-59 84% Caucasian	58
Wirtz[50] (2014)	Range	Men who have sex with men		8

Author (Publication Year) Country	Healthcare Speciality	Study population	Selected sample characteristics (Age, ethnicity, education level)	Sample size
Malawi				
Law[35] (2015) Canada	Primary care	Lesbian, gay, bisexual or transgender men and women	Mean age 32 91% university education	12
Marques[25] (2015) Portugal	Not specified	Lesbian women	Mean age 37 (range 21-63)	30
Mattocks[26] (2015) USA	Military	Lesbian women	Age range 41-50 35% white, 30% Hispanic, 15% African American	20
Quinn[43] (2015) USA	Not specified	Men and women of any sexual orientation		632
Underhill[40] (2015) USA	Range	Men who have sex with men	Median age 27 (Male Sex Workers) Median age 39 (MSM) 76% white 40-50% college education	56
Fish[34] (2016) UK	Oncology	Lesbian, gay or bisexual men and women	Mean age 54 (range 41-71)	15
Furlotte[48] (2016) Canada	'home care'	Lesbian, gay, bisexual or transgender men and women and their partners	Mean age 64 (range 39-75) 96% white	24 (12 couples)
Legere[46] (2016) Canada	Oncology	Lesbian and bisexual women	2 in 20s, 4 older than 40yrs 28% black	7 (6 patients, 1 HCP)

Author (Publication Year) Country	Healthcare Speciality	Study population	Selected sample characteristics (Age, ethnicity, education level)	Sample size
Munson[27] (2016) New Zealand	Primary care	Lesbian and bisexual women	Age range 23-47 83% higher education	6
Roller[28] (2016) USA	Not specified	Lesbian and bisexual women	Mean age 41 (range 21-59) all white 67% college degrees	13
Venetis[31] (2016) USA	Not specified	Lesbian, gay, bisexual or transgender men and women	Mean age 28 (range 21-44) 66% Caucasian	24
Wanyenze[44] (2016) Uganda	Not specified	Men who have sex with men	50% aged 21-25	85 + 61 key informants
Rose[38] (2017) International	Oncology or Primary Care	Gay and bisexual men	Mean 64 67% Caucasian	124 + 21 partners

Table 2 – Facilitators and barriers to sexual orientation disclosure in healthcare

FACILITATORS	References	BARRIERS	References
Moment of disclosure		**Moment of disclosure**	
Communication skills of HCP		Communication skills of HCP	
Response to a direct question	22 24 27-29 32 34 35 37 38 40 42 45 46	Response to a direct question	26 28 31 42
Inclusive language	31 35 37 41 42	Heteronormative language	27 35
Open body language	24 35 37 42-44	Closed body language	42
		No opportunity in conversation	34 38
Relevant to care	21-31	Irrelevant to care	22 24-26 28-30 32-40
Written disclosure	23 36 40 42 43 47	Written disclosure	27 37
Confronting heteronormative assumptions	22 28 30-32 34 41 48	Conforming to heteronormative assumptions	22 27 46 47
Perceived outcome of disclosure		**Perceived outcome of disclosure**	
Patient-provider confidentiality	23	Breach of confidentiality	21 25 30 35 38 40 44 47 48 50
Documented on medical record	25	Documented on medical record	25 26 29 30 47
Good/open HCP response	33	Poor HCP response	24 25 30 31 38-42 44 47 49 50
		Embarrassment	32 34 38 40 47
		Discrimination	
		Poorer care	24 27-30 33 41 44 46 48 49
		Loss/impact on job	26 44
		Loss of benefits	26 29
		Criminalisation	44 50
HCP Factors		**HCP Factors**	

Perceived accepting of LGBT	33 35 40 41 44 47	Perceived non-accepting of LGBT	33 38 39 49
Long relationship with patient	24 40 48	Long relationship with patient	35
Short relationship with patient	40	Short relationship with patient	47
Gender	37 39 40	Ill-informed of LGBT issues	21 32 37 47 49
LGBT	21 26 33 39 42 47 49		

Environmental Factors		**Environmental Factors**	
Location/setting	36	Location/setting	33 36 39 40 45
Accepting visual cues	24 27 40 42 43 49 51	Religious icons	24
Supportive community	33 42	Unsupportive community	44 50